

Aberystwyth University

Who cares for the carers?: An investigation of the barriers and facilitators to compliance with carers needs assessments

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Who cares for the carers?

An investigation of the barriers and facilitators to engagement with the Carers Needs Assessment.

Report to Ceredigion County Council

August 2014

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Executive Summary

- In September 2012, Aberystwyth University Psychology Department in collaboration with Ceredigion County Council Social Services Department received funding through the Knowledge Economy Skills Scholarship (KESS). KESS is part funded by the European Social Fund (ESF) through the European Union's convergence programme administered by the Welsh Government.
- Financial input from Ceredigion County Council was met with additional funding from KESS to appoint a research masters (MPhil) student for one year with the aim of exploring the barriers and facilitators of engagement with the Carer's Needs Assessment (CNA) from the perspective of both carers and professionals involved in the promotion and dissemination of the CNA.
- The research aimed to develop a broad view of the awareness and willingness to engage in the CNA as well as a detailed view of people's experiences of the processes, barriers and facilitators. For this reason the research was conducted in two broad phases.
 1. A survey of carers in Ceredigion exploring their knowledge, understanding and experience of the CNA.
 2. An in-depth qualitative phase exploring carers' and professionals' experiences of the CNA with particular interest in the barriers and facilitators for engagement.
- In total 60 completed surveys were returned, this consisted of 37 male carers and 23 female carers aged between 26 and 60+. The vast majority of the carers responding were over the age of 60 (75%) and reported being retired or a full time carer (23% and 59% respectively). The majority reported caring for a spouse (53%), parent (22%) or child (15%).
- Of the responses to the survey the majority were aware of the CNA (78%) with 77% of those having been offered and accepted the assessment, 6% being offered but declining the assessment and 15% not having been offered the assessment.
- Of the 3 individuals who had been offered the CNA but chosen to decline the offer, 2 reported that this was because they believed that the assessment was not appropriate for them, whilst one reported being unsure of the process.

- No individual selected the options that the process would be too time consuming, or that they had been put off by the opinions of other carers or social workers/professionals.
- Of those who had accepted the CNA the majority completed the assessment with the support of a social worker or other trained professional. Only two individuals (6%) completed the assessment independently.
- Most individuals reported that the process was not difficult to complete (88%) and found the process useful (72.8%). The majority of respondents took between 1-2 hours to complete the process (36.4%). However, 91.2% of respondents indicated that the length of time that it had taken them to complete the assessment was appropriate regardless of the time it had actually taken them.
- Interviews were conducted with 6 carers representing individuals who had and had not completed the assessment in order to ensure representation of both situations.
- Interviews followed a semi-structured design following a question schedule designed to address the key issues of interest but with the freedom to expand on the participant responses. The schedule consisted of in depth questions which sought views of both the practical barriers to uptake and completion of the assessment, and the possible factors that may have influenced their decision to engage or not engage with the assessment process.
- Key themes emerging from the carers' interviews included:
 1. *Disappointing outcomes* for carers reducing the perceived benefit of completing the assessment,
 2. *Adequacy* of the assessment in terms of the length and nature of the questions,
 3. The importance of *communication* from professionals for determining whether the opinion of the assessment was appositive or negative one.
 4. *Semantics* of the terms 'carer' conflicting with their identify as a spouse, parent etc.

In addition, a consistent finding apparent through the carer interviews was the undercurrent of 'carer burden' and the strain that this role can place on those providing care.

- Two focus groups and 3 individual interviews with professionals who come into contact with the CNA were conducted. The interview schedule sought to explore similar areas of interest as those discussed during the carer interviews, i.e. exploration of professionals' engagement and experiences of delivering the CNA.
- Key themes emerging from the professional focus groups and interviews were:
 1. The *label* of a carer being a barrier to engagement
 2. *Mixed messages* regarding the purpose of the CNA amongst carers and professionals.
 3. *Hidden voices*; a sense of 'tokenism' as the CNA did not provide an adequate vehicle for the carer voice.
 4. *Time* as a barrier to completion.
- Considerations stemming from the report include developing more information for carers about the process and realistic outcomes of the CNA, the need for additional training for assessors, whether the current method of assessing through a range of social services roles is adequate, and the need for increased and improved communication between service departments and third sector organisations.

1. Background

In September 2012, Aberystwyth University Psychology Department in collaboration with Ceredigion County Council Social Services Department received funding through the Knowledge Economy Skills Scholarship (KESS). KESS is part funded by the European Social Fund (ESF) through the European Union's convergence programme administered by the Welsh Government. The scheme aims to support research which brings together academic expertise with the business focused research needs of business partners in the convergence areas of Wales. A meeting of the Ceredigion Older People's Partnership (COPP) highlighted the poor uptake of the Carers Needs Assessment (CNA) in Ceredigion. This was preventing Ceredigion County Council from meeting set targets resulting in financial penalties. In addition, concerns were raised that the lack of carer engagement could be resulting in carers from the locality not receiving the help that they may be entitled to.

As a result a project was proposed with the aim of exploring the barriers and facilitators to the engagement with the CNA. The findings of this research are presented in this document.

2. Overview of the caring role and the Carers Needs Assessment

There are a number of different definitions of a carer. For the purposes of this report a definition of a carer is, *“someone who looks after and supports a friend, relative or neighbour who could not manage without their help. This could be due to age, physical or mental illness or disability. It does not mean a professional care-worker or personal assistant who gets paid for their work.”* (Directgov, 2011)

Individuals contributing their time to care for others is clearly of value to society who would otherwise be responsible for the well-being and health of significantly more individuals. The 2011 census (Office of National Statistics, 2011) shows that there are 370,230 (12.1%) people providing unpaid care in Wales. This value represented a 3% increase in unpaid carers with rural localities in Wales showing the highest increase. The recent Clements report (Clements, 2012) highlighted that between 1991 and 2001 there was a 28% reduction in the number of households receiving support from social services, and that despite the significant increase in the older population fewer of these are reliant on external support. As a consequence the burden on carers is clearly increasing.

This increased responsibility for carers has financial, psychological and social consequences (Carers UK, 2014). Significant number of carers report being socially excluded, living in precarious financial situations with no pension prospects and often report living with chronic disease or ill-health themselves (Carers UK, 2014).

Initiatives have been in place to support carers to continue on their caring role.

However, recently, carers have become more of a central focus of governmental support in their own rights as opposed to in association with the individual being cared for (Clements, 2012).

In line with the Carer's equal opportunities Act (2004) carers who were considered to have a 'substantial' and 'regular' caring responsibility were entitled to additional sources of support from local government including and starting with a Carer's Need Assessment (CNA). The act reflected on the fact that individuals may not have been aware of their entitlement, and as such the legal responsibility to inform carers of their entitlement lay with English and Welsh Social Services. However, the recent

Social Services and Well-being (Wales) Bill (2014) replaced the existing law and expanded the entitlement of the CNA to adult carers, young carers and parent carers irrespective of the classification of 'substantial' and 'regular' care.

The CNA is an in-depth appraisal of a carer's situation. The aim of the assessment is to analyse whether the carer is willing and able to carry on providing the same level of care. This involves addressing concerns such as the carer's own health, desires to continue or return to work, and leisure activities amongst others. Following the completion of the assessment, the assessor is responsible for determining what services could be appropriately offered to the carer to support them in their caring role. Support, may include additional services for the cared for which would relieve the pressure on the carer (e.g., sitting services), sign posting to 3rd sector organisations, direct payments towards respite care, or help with household duties.

Unfortunately, uptake of the CNA is lower than desired across Wales; however the uptake of the assessment is particularly low in Ceredigion. Although anecdotal reasons for this have been proposed, no evidenced based research has explored the reasons for this.

2.1 Research aims:

The aim of this research therefore was to explore the barriers and facilitators of engagement with the CNA from the perspective of both carers and professionals involved in the promotion and dissemination of the CNA.

2.2 Overview of Research Methodology

The research aimed to develop a broad view of the awareness and willingness to engage in the CNA whilst generating a detailed view of people's experiences of the processes, barriers and facilitators when engaged with the assessment process. For this reason the research was conducted in two broad phases. The first phase involved a survey exercise amongst carers in Ceredigion exploring their knowledge, understanding and experience of the CNA.

This was followed by an in-depth qualitative phase which explored carers' and professionals' experiences of the CNA with particular emphasis on the barriers and facilitators for engagement. Details of both phases are outlined below.

3. Phase 1

3.1 Design and recruitment

For this phase of the research a survey design was used to gain a broad understanding of the level of engagement with, attitudes towards, and experiences of the CNA.

In order to maximise the response rate to the study a number of different methods of recruitment were used over a period of 4 months. These included:

- Poster advertisements in GP surgeries throughout Ceredigion¹
- Contacting networks within Ceredigion Health and Social care and appropriate third sector organisations identified by Ceredigion Social Services to inform them of the research. These networks were sent a covering letter and FAQ leaflet with a request to highlight the research to relevant parties².
- A mail shot to all carers registered with Ceredigion Social Services consisting of a covering letter and FAQ leaflet
- An advertisement in the Jigsaw newsletter
- A press release in the Cambrian News
- A press release in Aberystwyth University's newsletter
- Advertisement of the research in the University's weekly newsletter to staff and students.

¹ All GP surgeries in Ceredigion received a recruitment pack which consisted of a covering letter, FAQ's about the research and a bilingual poster, which advertised the research and provided contact details of the research team. The decisions to display the poster was surgery dependent.

² Electronic copies were sent initially with the offer to providing hard copies on request.

3.2 Participants

In total 75 carers expressed an interest in participating and received a survey pack, which consisted of a participant information sheet, consent and debrief forms, a survey and a stamp addressed envelope for ease of return.

In total 60 completed surveys were returned, this consisted of 37 male carers and 23 female carers aged between 26 and 60+.

3.3 The Survey

A survey was designed to address three key areas (see appendix 1):

- Who were the carers responding; this corresponded to questions about gender, age, employment status and information about the cared for.
- Knowledge and uptake of the CNA; these questions revolved around awareness of the CAN and whether carers had been offered the CNA.
- Reasons for non-engagement with the CNA or experiences of the CNA process

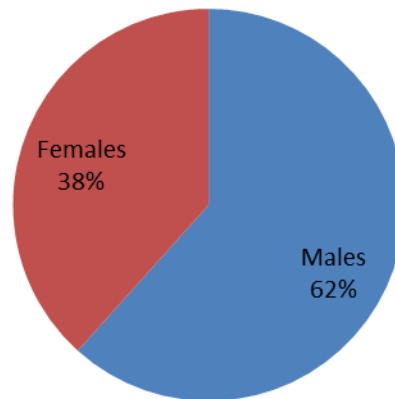
The survey was deliberately designed to be simple and quick to complete; it comprised primarily of tick box answers with opportunities for brief written comments should the responder wish to expand.

3.4 Results

3.4.1 Demographics of responders

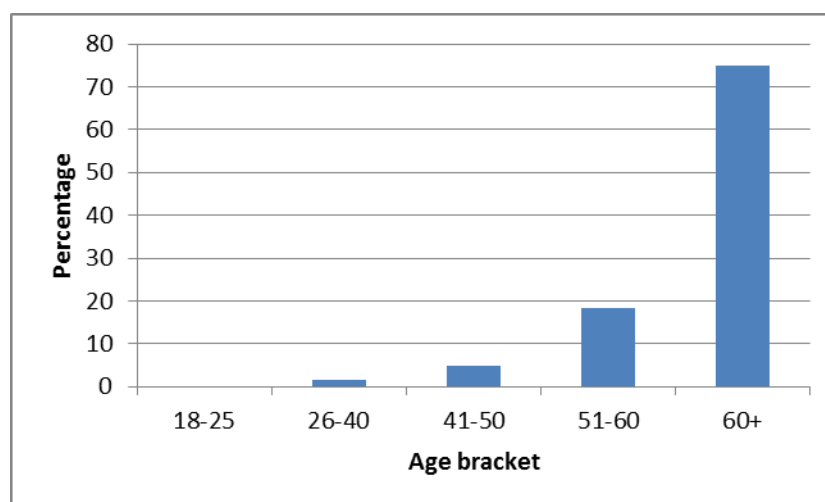
More males than females responded to the survey (Figure 1). This does not appear to be representative with national figures with Carers UK reporting that 58% of carers are female and 42% male (Health and Social Care Information Centre, 2010).

Figure 1: Percentages responses according to gender



The percentage of individuals responding from each age bracket are represented in Figure 2. Age ranged between 26 and 60+ with 75% of responders being over 60. National statistics suggest that the majority of carers are aged 42-64 with 25% above the age of 65 (HSCIC, 2010). The results from this study may therefore be representative of an older rural community, or those of retirement age who perceived themselves to have more opportunity to contribute to the research.

Figure 2: Percentage of responses representing age brackets.



In terms of employment status; most of the carers described themselves as either being a full time carer, or as being retired, with the remainder indicating varying degrees of employment/self-employment or education (Figure 3). Again this was quite different from English national statistics which demonstrated that approximately half (46%) of carers were in paid employment, 27 per cent were retired from paid work and 13 per cent were looking after their home or family. As previously highlighted, this could reflect the response bias of the research attracting those not in employment who thus had more time to complete the questionnaire and contribute to the study. However, this demographic profile may reflect the changes seen in levels of informal caring in the past 3-4 years, or be indicative of regional differences between England and a rural community such as Ceredigion. Ceredigion supports an older population than its urban counterparts. The challenge of access in a rural context could reflect the reasons why a higher proportion of the sample were retired, or had needed to commit to caring on a full time basis.

Figure 3: Percentage of responses by employment status

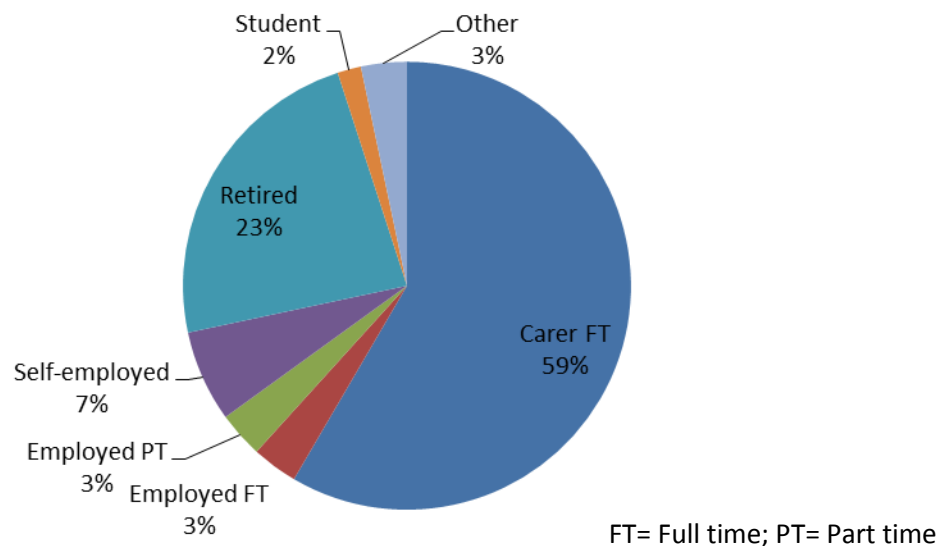
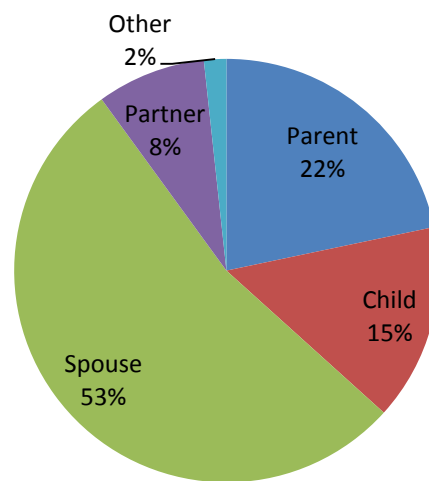


Figure 4 illustrates how the majority of individuals were caring for a spouse with a smaller majority caring for a parent or child. Of the respondents almost 17% reported caring for more than one individual.

Figure 4: Relationship of carers to the cared for

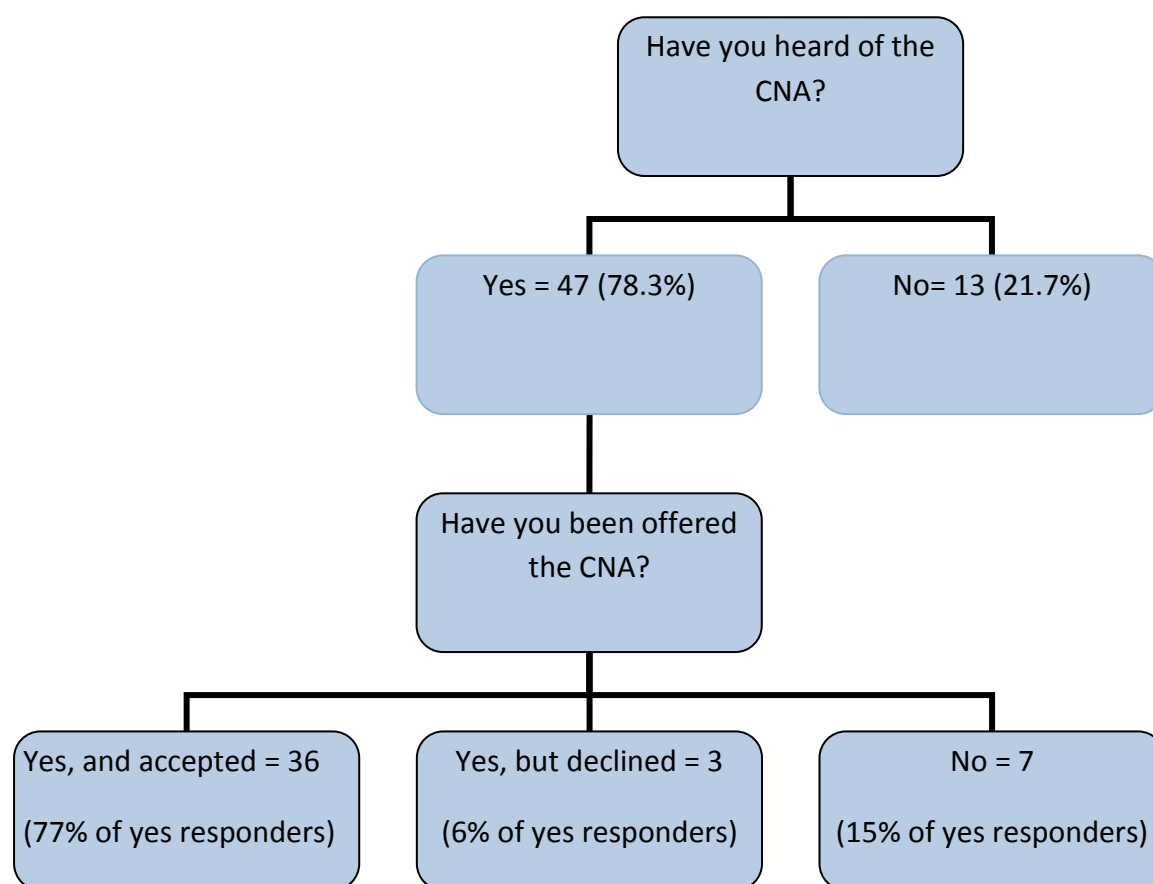


3.4.2 Knowledge and engagement with the Carer's Need Assessment

Figure 5 demonstrates the degree to which individuals had heard of the CNA, whether or not they had been offered the CNA and whether or not they accepted the offer³.

³ 1 respondent provided no response to the question about being offered the CNA

Figure 5: Flow diagram indicating level of knowledge and engagement with CNA



It can be seen that the majority of respondents had heard of the CNA. This may suggest that a lack of awareness does not explain the low uptake in Ceredigion; however, it should also be noted that the nature of the research would evidently engage the interest and response of carers who were more likely to have heard of or engaged with the CNA than those with no knowledge of the assessment.

However, of those who had heard of the CNA, the majority had been offered an assessment, and had chosen to accept it. A smaller percentage had declined the offer or had not been offered the assessment.

3.4.2.1 Reasons for non-engagement

Of the 3 individuals who had been offered the CNA but chosen to decline the offer, 2 reported that this was because they believed that the assessment was not appropriate for them, whilst one reported being unsure of the process.

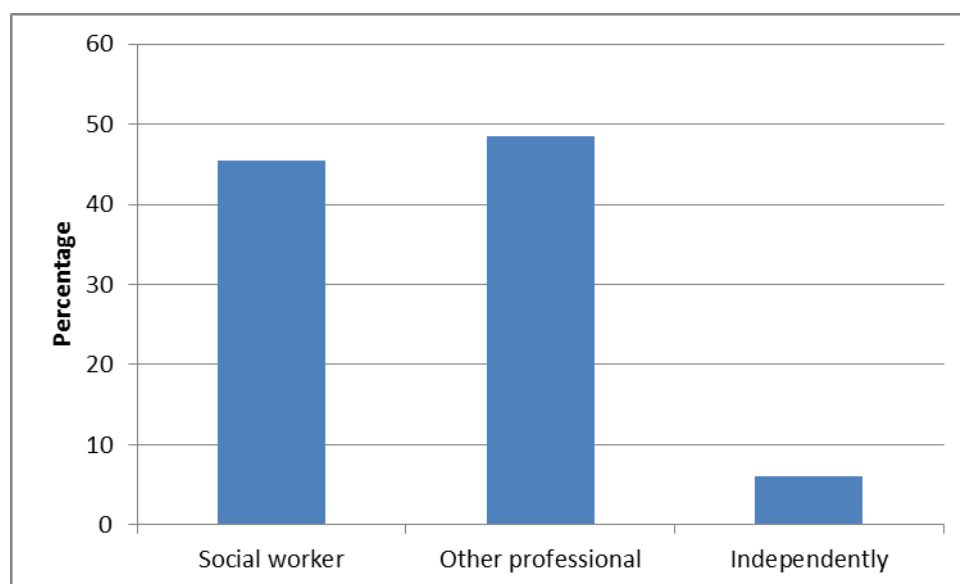
No individual selected the options that the process would be too time consuming, or that they had been put off by the opinions of other carers or social workers/professionals.

3.4.2.2 Experiences of the CNA processes

This section details the responses from the 36 individuals who accepted the offer of the CNA. Results therefore reflect the percentage of the 36.

The majority of individuals completed the assessment with the support of a social worker or other trained professional (Figure 6). Only two individuals (6%) completed the assessment independently.

Figure 6: Percentage indicating the method of completing CNA



Most individuals reported that the process was not difficult to complete (88%; Figure 7) and found the process useful (72.8%; Figure 8). The majority of respondents took between 1-2 hours to complete the process (36.4%; Figure 9). However, 91.2% of respondents indicated that the length of time that it had taken them to complete the assessment was appropriate regardless of the time it had actually taken them.

Figure 7: Percentage indicating perceived difficulty of CNA completion

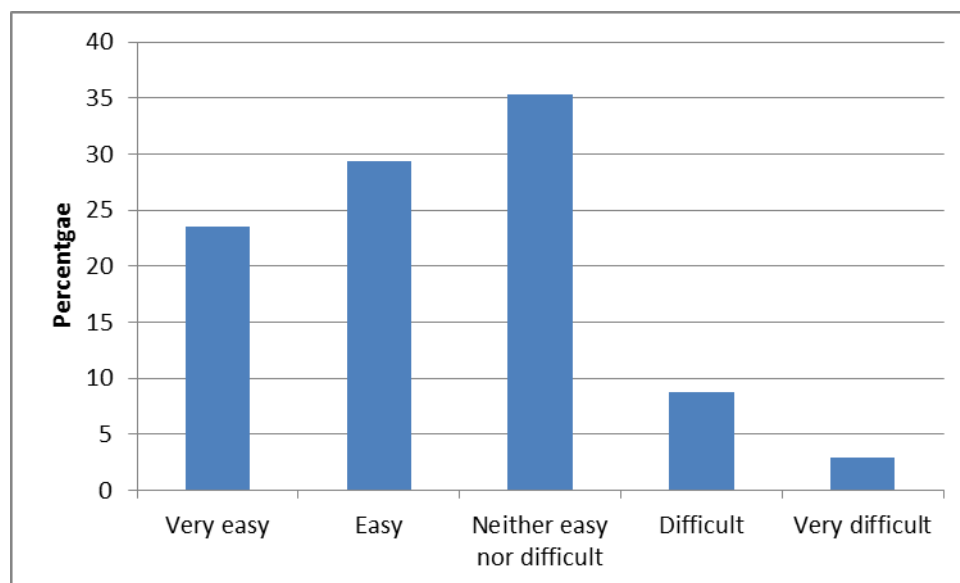


Figure 8: Percentage reporting ease of process

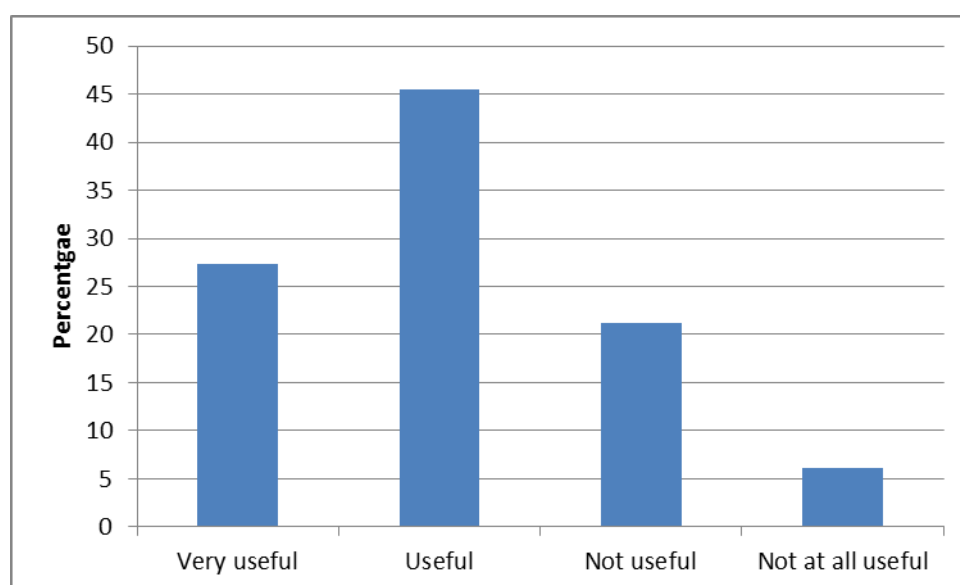
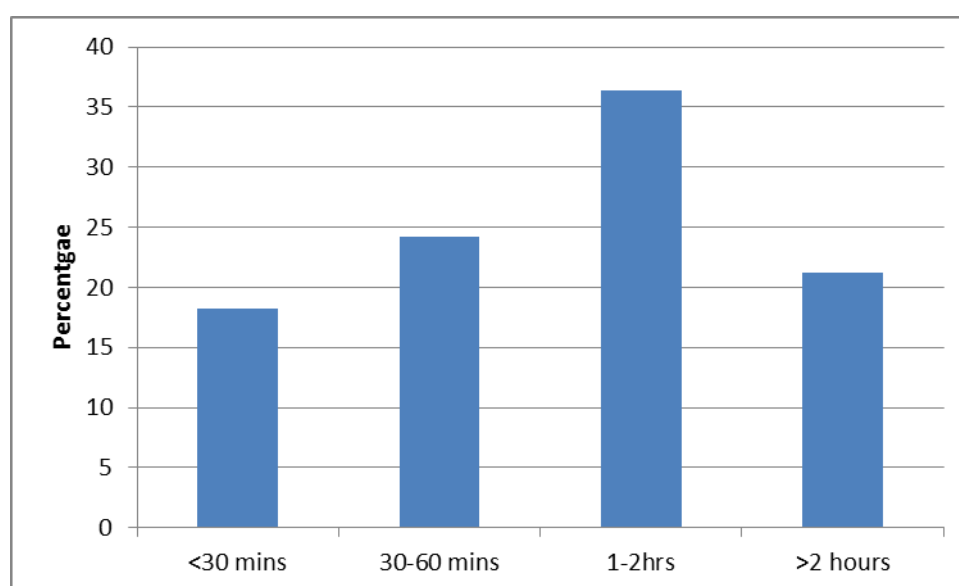


Figure 9: Percentage indicating the time taken to complete the assessment



3.5. Conclusions of Phase 1

In summary, phase 1 achieved modest recruitment; however this is reflective of the context of conducting research to address the lack of engagement from a hard to reach demographic. This caveat should be considered when attempting to draw generalisations from the findings of the research. This is further warranted given that the demographic of the respondents were not representative of the demographic typically associated with the caring community as indicated by National censuses in England (ONS, 2011). Given that comparable demographics were not readily available for Wales, it should be considered that the reported demographic profile may reflect the differing categorisation of carers that could exist in a rural context such as Ceredigion.

Most individuals had heard of the CNA, and having been offered the opportunity to complete the assessment had engaged with the process. Although this may appear contradictory to the reasons provided for engaging in the research (i.e., lack of engagement in Ceredigion); this is likely to reflect a sampling bias where individuals who have engaged with the process are more likely to volunteer to participate in research than hard to reach individuals who had declined this opportunity.

However, of the minority who declined the opportunity to complete a CNA there appeared to be a perception that the assessment was not appropriate for them or that the individual was unsure of the process to follow to accept the offer.

Of those who had completed the CNA, the process appeared to be well received. Most individuals reported that the process was not difficult, that the time taken to complete the assessment was appropriate, and that the process had been useful.

4. Phase 2

4.1 Design

This phase aimed to build on the findings in Phase 1 by exploring the barriers and facilitators to completing the assessment in more depth.

A qualitative approach was used to gain in depth perspectives from a) carers and b) professionals who had experience of the CNA.

4.2 Carers' experiences

One to one semi-structured interviews were used to gather information from carers.

4.2.1 Recruitment and Participants

Carers were recruited via the survey research in Phase 1. Participants were asked whether they would be willing to take part in a recorded interview to explore their experiences further.

Fifty of the survey responders indicated that they would be interested in participating in an interview. A purposive sample of 6 responders were invited to participate in an interview at a time and location of their choice. To ensure a representative sample

of the responders from a wide perspective the sample selected included both carers who had, and had not, taken a needs assessment, those who had had a positive experience and those who had had a negative experience as indicated on their survey responses. Profiles of the participants are provided in Table 1 below:

Table 1: Profile of interview participants

Sex (M/F)	Carer/Cared for	Caring relationship	Working role	Completed carers' needs assessment	Additional information
F	Carer	Mother	Full-time work	Yes	Contacted by SS Self-assessed
M	Carer	Wife	Not working	Yes	Also cares for mother and mother-in-law
F	Cared for	Wife	Not working	Yes	Wife of male carer above
M	Carer	Wife	Retired	No	None
M	Carer	Wife + another male	Not working	Yes	None
F	Carer	Husband + another male with learning difficulties	Working	No	Also cares for mother Works as a practice nurse in GP surgery

4.2.2 Interview schedule

Interviews followed a semi-structure design following a question schedule designed to address the key issues of interest but with the freedom to expand on the participant responses. The schedule consisted of in depth questions which sought views of both the practical barriers to uptake and completion of the assessment, and the possible factors that may have influenced decisions to engage or not engage with the assessment process. The interviews lasted between 30-60 minutes and were recorded for transcription and analysis.

4.2.3 Results - carers

Analytical Process

Inductive thematic analysis of the qualitative data was conducted to identify recurring themes emerging from the interview transcripts arising from the conversations with carers. A process of detailed initial analysis of one transcript was undertaken to generate indicative themes. The indicative themes provided a framework for the second stage of the analysis during which new themes were developed until theme saturation occurred. The final themes are presented in Table 2 below followed by description and discussion.

Table 2: Carers' Themes

Theme	Characteristic
Disappointing outcomes	What was the point?
Suitability/adequacy	Does this apply to me? Am I good enough?
Communication	What are my rights?
Identification/semantics	Who am I?

Disappointing Outcomes

Disappointing outcomes was an important emergent theme identified across the data set. Participants reported lack of follow up after a request for assessment, reluctance of a social worker to conduct an assessment, and being unsure of how the CNA could help a carer as key concerns.

For carers lack of confidence in meaningful outcomes is likely to be a substantial barrier to the completion of the CNA. If perceptions are that there is no advantage to be gained, the questions arising are “What is the point?” Or, “How is this process going to help me?” The carers normative beliefs may be challenged as will their perceived behavioural control, that is, the carer’s ability to influence the outcomes of the process. Of those who had completed an assessment, confidence in the process was further undermined by issues such as absent or slow follow up after the assessment, inappropriate help being offered, or and in some cases, no action arising after the assessment.

Suitability/adequacy

The transcribed data yielded a theme of “suitability” or “appropriateness” – essentially the carers were questioning whether the CNA was “fit for purpose.” The structure, number, and length of questions was queried and there was a sceptical perception of the process as being a *“tick box exercise for the Council.”* Suitability was also queried at an emotional level with carers perceiving the process as being too invasive and judgmental of their adequacy. For some participants there was a feeling of *“being checked up on”* with their ability to look after their loved one being questioned. Participants reported finding some questions as being **“REALLY personal”** (emphasis added) and in some cases distressing. This was particularly acute for those carers that reported difficulties with role identification with the relationship transition from loved one to carer. In contrast, the theme of suitability was apparent albeit with a difference in interpretation. For those participants reporting that they had no need for help as their cared for was receiving adequate support and as a consequence their carer burden was minimal, the question theme of suitability applied to the process itself. That is *“is this process suitable for*

someone like me?” For these carers – particularly if they did not recognise the label of being a carer – the view was that the CNA was not an appropriate process for them to engage with. This suggests that the ‘official’ definition of carer is not one with which some people can identify as applicable to them or their circumstances.

Overall the data suggested a lack of perceived behavioural control, and self-efficacy, interacting with a lack of belief in the process. There was a strong sense of lack of agency expressed by the carers in terms of the CNA being a process that they could use to influence outcomes. Allied to a suspicion that the CNA is a process by which carers adequacy is being assessed may result in non-compliance as carers seek to re-gain a level of control by choosing not to engage with the assessment.

Communication

One of the most frequently reported subthemes was of carers being unaware of how the CNA and its outcomes could facilitate and support the caring role. Participants reported that experiences of social workers were unable to fully inform the carer of their rights or the help available and other options open to them. In some cases the information the carers were given was inaccurate, resulting in carers having to research their own rights and entitlements. Some carers were unaware of their entitlement to request an assessment despite being on the carers register with social services. Participants identified an information or education gap in both carers and professionals which needed to be addressed to promote understanding of carer rights and sources of support.

In contrast to the limitations of poor communication the participants also identified the benefits of excellent communication. Having a visit from a compassionate and interested professional who took time to listen was seen as an important tangential benefit of the CNA. In terms of communication and information the role of the professional was central as poor communication skills and lack of knowledge undermined the carers’ belief in the CNA process. Conversely, an engaged and enthusiastic professional provided benefits for carers other than any benefits resulting from the CNA process. In both circumstances the professional set the context of the encounter with the carer which was highly influential in assessments of

the outcome of the CNA process. The carers suggested that a specific team armed with the knowledge of the CNA and acting as a central point of contact would facilitate the process. Participants reported being valued and appreciated by professionals who were understanding, compassionate and willing to listen. The emergent outcome was that if carers felt listened to and understood, and that their rights are being explained to them in ways that made sense to them, their behavioural control and sense of self-efficacy was enhanced.

Identification/semantics

A sense of identification and the role of semantics was a dominant theme in the carer narratives. Some carers reported that there was a stigma attached to the term “carer” and stated their preference for their perceived legitimate primary role of husband, wife, mother or child rather than carer to their loved one. It became apparent that for these carers looking after their loved ones causes substantial role conflict which is challenging to the individual’s sense of who they are, and their relationship to the person they care for.

Although a minor theme the use of the term “carer” was evidently highly charged for some individuals as the words used created false or worrisome perceptions. Participants reported not perceiving themselves as a carer as the role they are undertaking may be performed out of love for the cared for, may be considered to be a duty, or is simply just “something they do.” In terms of semantics the use of the term “assessment” in the CNA be a barrier to engagement as it has overtones of the carer being tested on their ability to look after their cared for. Some participants noted that they felt as though the assessment was there to make sure that they were capable of carrying out their caring role.

Another problem that was identified was the lack of a universal definition for unpaid carers. Participants reported that they did not view themselves as carers as they have a professional as well as a caring role. For some a carer may be a role held by someone who is paid to care. If the term “carer” is emblematic of a change of relationship - and a label that undermines a sense of self - this, allied to the term “assessment”, could generate a negative environment generating lack of

engagement with the CNA. Overcoming these negative perceptions is a challenge that would have to be addressed to improve compliance levels and support maximum engagement with the CNA.

Additional information – conceptualisations of the “Carer Burden”

Whilst not directly related to the emergent themes of the interviews a thread running through the conversations held with participants was of the “carer burden”. The carer literature reports that being a carer can result in aspects of the carer burden, and the participants in this study reflected common experiences shared with others. In this sample, the key features of the carer burden identified by the participants were:

1. *Physical burden* – caring for the physical needs of the cared for, fatigue and the carer’s own health needs. A key finding was that for many carers duties include a lot of the physical aspects of caring with a requirement to be ‘on call’ to the cared for twenty four hours a day.
2. *Feeling vulnerable* – dealing with the medical and physical/psychological needs of the cared for was a challenge that made some participants feel inadequate and vulnerable. For some carers the burden of caring, family life and working left them feeling as though there was no one else to speak to or nowhere to go.
3. *Psychological and social isolation* - participants identified the challenges arising from divided roles as they fulfilled their paid role and then came home to care, there is no opportunity to socialise outside of this. For those still working and caring for a loved one that didn’t live in the same house as them, there were problems with balancing work, family and caring duties, as well as finding time for themselves resulting in lost contact with other people outside of the immediate family network.
4. *Rurality* - for many carers just not being in close proximity to others CNA cause isolation and very often no other support network in place resulting in all the caring falling on the carer

What was significant in terms of building a picture of the lived reality of the carer experience was that participants reported that when they did have the chance to socialise they would prefer not to socialise with other carers, and dwell on their

situation. It was essential that they had the opportunity to leave the caring role behind completely and have time to be themselves. It was particularly poignant to hear some carers report that should they have the time to engage in assessments or appointments they would see it as an escape, a bit of free time and would relish this opportunity as a temporary respite.

The relevance of the above finding was that although it was initially hypothesised that carers may not be taking up and completing assessments because they had spoken to other carers who may have advised against the CNA, this factor may not be influential if the experience of the participants in this study is common. For some carers a way of maintaining their sense of self, and of being more than 'just' a carer, was through actively choosing not to socialise with other carers.

4.3 Professionals' experiences

Focus groups were deemed the most suitable way to gather information from professionals as this allowed opportunities for deliberation and discussion amongst the different sectors. Where time constraints of professionals limited their ability to engage in focus groups one to one interviews were conducted to ensure equal opportunities were provided for engagement with the study thus maximising the quality of the information gathered.

4.3.1 Recruitment and Participants

Eleven professionals were recruited via email, telephone, personal contact and through the support provided by Ceredigion Social Service. Two focus groups were conducted, details of participants are provided below:

Focus Group One (n =3) (health, social care and the third sector)

Focus Group Two (n = 8) (health, social care and the third sector)

Additional data was generated through 3 individual interviews with professionals from the social care sector

4.3.2 Interview schedule

The focus groups used a series of questions using a pre-determined question schedule of key questions and additional prompts (Appendix 2). The question schedule provided triggers for debate and discussion to address the key areas of investigation, namely the capacity in which professionals came into contact with the assessment and their views, values and opinions of the assessment process and its purpose.

The focus groups were conducted in Ceredigion Social Service offices in Aberystwyth and Aberaeron. Each group lasted approximately 90 minutes.

4.3.3 Results

Analytical Process

The same process of analysis used with the carer data was adopted. Following transcription, inductive thematic analysis of the data was conducted to identify recurring themes emerging from the focus groups. A detailed initial analysis was undertaken which generated indicative themes. The indicative themes provided a framework for the second stage of the analysis with the transcript interrogated in detail to generate additional themes until theme saturation occurred. The final themes are presented in Table 3 below followed by description and discussion.

Table 3: Professional themes

Theme	Characteristic
Labels	Is this really me?
Mixed messages	What are the outcomes?
Hidden voices	Have I been forgotten?
Time to care	Do I have the skills?
Stigma	What are the implications?

Labels

The professionals reported on the reluctance of carers and the cared for to acknowledge or accept the term 'carer'. A consistent finding across all the groups was that 'carer' is a potential barrier to engagement with the CNA process.

Whilst there are several definitions of a carer, and this report adopts the definition of DirectGov (2011), the professional opinion was that carers do not share the view that this definition only applies to someone who does not get paid for their care role. The role of carer *'used to mean husband or wife and that was it'* (SS focus group), in other words, caring for a spouse in sickness (and in health) was simply a tacit part of being married. As the CNA uses the word 'carer', very often carers and the cared for do not interpret this as applicable to them, or want to be labelled as such. As the professionals report this label incorporates an element of detachment and professionalism that strips away the husband/wife dynamic.

'people's perception of a carer is somebody that goes around in uniform door-to-door every morning, getting people up, washed and dressed' (SS focus group);

The responses of caring participants to the term 'carer' were discussed with the professional participants to elicit their views. In the same way as the carer group, the professionals reported that there was antipathy to the term from their clients/service users who are caring for their loved ones. Clients/service users

appear to reject this term as they do not want to identify, or be identified as 'carers'; as several participants explained, this label, for them, implies that they no longer love their husband or wife. In being constructed, or labelled, as a 'carer', 'caregivers' talk of losing the intimate bond they share with the person they 'care for'. Furthermore, caring for their loved one is seen as just an element of their primary role because that is part of being a husband or wife, daughter or son; it is just something family members do, it is their duty. Although not explicitly explored in this study there is an increasing awareness of the challenges of the "sandwich generation" of mid-life people simultaneously bringing up children whilst caring for older relatives. It is debatable whether the term 'carer' would be one that this group would find acceptable or applicable to the specific challenges they face.

The indistinguishable label of 'carer' in conjunction with the word 'assessment' which together form the title of the 'Carers Needs Assessment', undermines carers' often already fragile and vulnerable sense of self-worth. Often living in isolation, since their social worlds have gradually become smaller, they feel threatened by the form, seeing it as a test or judgement on their ability to care. A comment that illustrated the implication of a changed status was the statement that *"some people don't think of themselves as being a carer and actually don't want to think of themselves as a carer because it's a line they are crossing."* Both carers and the cared for, and professionals reported that the changed status of being labelled a carer was riven with negativity as it implied a fundamental change in the nature of intimate relationships which for many was unacceptable.

Mixed messages

The professionals who participated in the focus group reported that carers that had heard of the CNA, or had completed the assessment, were often left with mixed messages regarding the purpose of the process and what the outcomes might be.

This dubious clarity was also directly and indirectly implied by the professionals responsible for taking up referrals. Throughout the transcripts there was repeated talk of the CNA being a waste of time with professionals arguing that that the assessment does not automatically mean help will be provided for the carer's

identified needs. The participants reported that a number of carers experienced a lack of 'outcome' in response to completing the assessment, and subsequently asked themselves 'why they bothered' to engage in a lengthy and seemingly purposeless process. Professionals report instances where cases made little progress with an attendant lack of a tangible outcome or additional help. Comments within the social services focus group highlighted social workers' disgruntlement with the form, reported observations that were made included that it is too lengthy, vague, non-user friendly, intrusive and convoluted. The professional group also commented that a 2 or 3 hour assessment adds to their already busy workload. There was a strong sense of frustration that the assessment did not facilitate the delivery of an improved service for the carers *"But most of all, what is frustrating is at the end of it [CNA], you don't really feel like you've helped the carer."* However, in contrast for some of the focus group participants despite the lack of tangible outcomes for carers the CNA process did have value in terms of its quasi- therapeutic nature. Just as the carers reported valuing having an opportunity to speak and be listened to, the professionals identified the CNA as a chance for carers to "offload". This suggests that there is an unintended benefit to the CNA process, as completion of the form provides a shared focus for attention supporting a wider ranging discussion. Whilst this may be helpful and supportive for the carer there are resource implications for service providers. If the CNA is primarily providing an opportunity for carer support in this way the question is whether scarce and expensive resources such as highly qualified social workers are the most appropriate people to provide a listening service.

Hidden Voices

One of the findings was the level of scepticism – with some level of cynicism – that completing the assessment was a tick box exercise, which enabled professionals to fulfil their legal obligations. Carers were reported as interpreting the lack of response (outcome) or forthcoming help as an indication that they have been forgotten – filed in a drawer or shelved.

Professionals reported that there was an overwhelming feeling among the carers that they are a hidden population; often they have been forced to give up paid

employment which gave them a presence in society and become increasingly isolated and, in a sense, non-existent or invisible. It is very difficult since individuals are rarely acknowledged in society for being a 'husband' or 'wife' for example, but are able to create an identity through work and social engagement. Caring, however, is often experienced as a loss in identity, as individuals become unnoticed as though they no longer existed. Taking on a caring role presents individuals with an "identity paradox" in that whilst they add a substantial burden into their lives this has the effect of subtracting a sense of who they are. Experiences of carers becoming anxious and depressed were reported as common especially when pressures increase. As one participant commented for one of their service users the CNA had value because *"She wanted one other human person, almost, to know what situation she's in. To just know, to just be aware and that's all she wants at the moment. There is that feeling amongst quite a lot of carers"* or as one carer said *"suddenly you can't be that person that goes and does – but you still need to be that person who goes and does. Suddenly you are in a crisis...."* Several of the professionals volunteered their view that the principles underpinning the CNA were sound as it provided a vehicle for otherwise hidden voices *"I do think it is important to understand that the carers do have a voice, should have a voice and should be heard"*. For one of the participants a major concern was the hard to reach or hidden carer *"Yet none of us are doing anything to identify the hidden carer because we don't know who they are, we don't know how to go about it"* – it is debatable how the CNA could provide any support for those of whom social services has no knowledge. For these hidden carers their needs may not be acknowledged until their own health breaks down and an acute crisis situation occurs.

For carers it is not only their physical needs that need addressing but, perhaps more importantly, their psychological needs. Psychological needs can be more difficult to discern. There is a stigma to mental health problems related to reports of carer concerns about being judged and assessed as inadequate. The implications of revealing a hidden need for support may act as a substantial barrier to engagement. The aim of the CNA is to provide a holistic assessment of the carer's needs. Whilst it may be acceptable to seek and receive physical help such as wheelchairs and grab rails, or help with washing and bathing, admitting to psychological needs may

provide a more subtle challenge to engaging with the CNA which should be explored further.

Whilst the purpose of the CNA is to identify the carer's needs, very often the carer sees the interview or assessment process as a chance to be 'noticed' and an opportunity to talk and have someone listen. As one carer commented, *"I think if you can get your points of view over, so that you've got yourself noticed that you've done it and it's there, whether anybody looks at it after again, at the other end is another matter"*. Whilst some professionals identified that the CNA can provide opportunities to engage carers in a supportive conversation, however, there was also an underlying sense of frustration that there may be limited outcomes from the process *"I hope they perceive it that I want to speak to them as a person in their own mind and value them in their own right If they're not perhaps thinking of respite or planning for the future so much, its quite difficult to see any worth from it."* It may be of some reassurance to professionals delivering the CNA that although there are limitations in the deliverables of the process, there is value for some participants in giving them the time and space to be heard. A carer participant reported that *"it would have helped me tremendously (CNA) because somebody would have acknowledged you, even if it was only this sort of thing, "Hey, I count, you actually noticed"*

Although there is an undoubted value in giving carers an opportunity to discuss their needs and their feelings, and the CNA can provide a vehicle that legitimises spending time with carers that they may not otherwise have made available to them, it is debatable whether this is the best process to provide an outlet for carers feelings. The process of completing the CNA may provide a quasi- therapeutic benefit for carers but that is not its main purpose and it is unlikely to be the most appropriate way to provide an emotional outlet for those in a caring role.

Time to Care

The data highlighted a number of barriers in terms of time. Social workers spoke about the time involved in completing the assessments because of the layout of the form and its length, and they queried the value of some of the questions. There was

considerable debate within the group regarding how best to approach the delivery of the CNA. Whilst some professionals reported completing the assessment in conjunction with the assessment of the cared for as integral to their role, others suggested ways to improve the value and quality of the assessment form. For example, the use of designated members of staff, sending out a pre-assessment form to carers to be read through prior to a visit. The latter suggestion may well have merit as it would provide the carers with a two stage process enabling them to begin to think about their needs, and what their own caring role entails before discussing their responses in more detail with the professional. There was considerable debate, and a difference of opinion amongst the professional participants. For some a joint appointment with both the carer and the cared for worked well as the process of completing the form generated discussion of previously unarticulated needs. For others, separate assessments were preferable as it gave the carer the opportunity to *“express their opinions and their concerns more without fear of upsetting the cared for person”*. A common observation was that often issues remain hidden as carers seek to retain privacy and prevent judgement by external agencies by *“keeping things within the family, not going to social services because there’s a stigma involved”*.

Whilst the social services in Ceredigion have, in recent months, experienced a dramatic increase in the number of carer referrals, largely from GP surgeries, there is a concern over the reasons for this rise. Some surgery staff referring carers do not see it as their role to explain what the assessment is and the value of it; they are ill prepared and there are concerns that if these referrals are not ‘handled’ correctly the outcome could be potentially damaging for those carers involved. The Red Cross workers, taking part in this study, also suggested that some social workers did not have the necessary skills appropriate for undertaking the assessments. During the focus group the question surrounding training and delivering the assessment arose several times; however, the response was vague, expressed as *“if you do an assessment you have the skills to do assessments, you have the skills to ask questions”*. However, this is not an automatic given and inadequate training could be a potential barrier. Another possible barrier that needs to be explored further in terms of training and skills gaps is the consequences for the professional delivering the CNA. To what extent do they feel supported, and how are they supervised and

de-briefed especially after a particularly difficult experience? As one participant observed *"its taken three hours [doing the assessment with a carer], its opening up a can of worms and you're coming back emotionally scarred, and there's no recognition for it whatsoever"*. Whilst this may not be a common or frequent experience it may be sufficiently disturbing for the person delivering the CNA that they become hesitant to suggest the assessment to a carer.

Stigma

There is an enduring stigma attached to the words "social services", and this was explicitly linked to the perception of the CNA as a test or judgement of the carer's ability to care, *"Yes, people don't want to be associated with Social Services."* According to the professionals, older generations, in particular, assume that care is undertaken by family members and the social services are regarded with fear; fear of loved ones being removed and placed 'in care' *"That [CNA] reinforces the stigma stigma and now they're going to come in and see if I'm caring for my elderly mother ok, and if I'm not, they are going to stick her in a home."* Focus group participants spoke about the migration of family members from Ceredigion to find employment, and the appearance of new communities of English retirees moving into the county. The resulting change in demographic has resulted in an increased number of elderly people, living in rural communities, who will potentially need help. Both observations have implications for delivery of services and the uptake of the CNA in an ageing population. The professionals reported the generational impact on uptake *"generational thing the older generation and keeping things within the family, not going to social services because there's a stigma involved."* Accepting this observation may require a re-think of how the CNA is presented and delivered to overcome stigma, and make the process less threatening for a section of the population that is increasing in size and in need within Ceredigion.

4.4 Conclusions of Phase 2

The evidence from both carer and the professional focus groups suggested a range of differing perspectives on the CNA and no true consensus regarding its worth. For carers there were very mixed messages regarding the process with some finding it intrusive, overly familiar a cynical paper exercise with no apparent benefit. For others, even if there was no tangible improvement in service delivery, there was value in the process as it provided an opportunity to be acknowledged and listened to as a respected member of the care team.

Similar polarisation of views was evident with the professional group with some professionals reporting the CNA as being integral to their role, and as an opportunity to sensitively identify the needs of carers. Professionals who viewed the process positively had adapted the delivery of the current form to their own needs, and those of the carers, in a thoughtful and individualised way. For others, for whom the process was a means-to-an-end – and not a particularly successful process – the delivery was far less imaginative and less tailored to the needs of the recipient. What the findings suggest is that staff may need to be given permission to de-construct the delivery process, and adapt this to the individual needs of the carer. By doing so both the professional, and the carer, may find completion of the CNA a more satisfying and worthwhile activity even if the outcomes may be less than optimal.

5 Final conclusions and recommendations

In summary, the research has identified a range of perspectives regarding the reasons for engagement with the CNA. Clearly, for some the process provided an opportunity to engage with a social worker in a way that provided a sense of acknowledgement to the importance of their caring role, this was particularly evident if the process was conducted efficiently with effective outcomes. Contrary to this, for others the nature of the assessment challenged their validity and competency as a family caregiver, and was burdensome with limited tangible outcomes.

In response to some of the key themes identified in the research considerations are made below. However it should be noted that these are based on the opinions and experiences of a selection of individuals believed to represent the views of a similar demographic. The nature of research such as this inevitably attracts individuals with a pre-existing interest in the subject and as such may reflect the extremes of both positive or negative opinions.

5.1 Considerations:

- **Information provision:** Given the apparent concern regarding disappointing outcomes and mixed messages regarding the purpose of the CNA, consideration should be given to developing clear and accessible information of what is available locally as outcomes to the assessment, and what the assessment is in order to manage carers expectations of the process.
- **Training for assessors:** Although some assessors felt that their role prepared them adequately for engaging with the assessment, others clearly felt ill-equipped to deal with the complexities that an assessment could reveal and lacking in information about what was available to sign post their carers to. Continued Professional Development training to assist in these elements could aid the confidence of professionals to offer and complete the assessments.
- **Dedicated team of assessors:** This was suggested by some professionals as a way to address the lack of training and awareness of appropriate signposting whilst disassociating the CNA from the stigma of social services and offering dedicated time to carers. However, any changes to the assessment process would have to be made in the context of recommended best practice which suggests that the CNA should be carried out in person with the Carer by the care manager or specialist Carer assessment worker. However, others felt strongly that this assessment could only be done effectively when considered alongside the needs of the cared for and that separating the assessments by teams would lead to a lack of continuity of care and sharing of information. Clearly, consideration of how best to support professionals in their roles, whose remit is increasing in capacity is needed.

- **Increased communication:** between professionals and their departments, and a sharing of information and skills with the voluntary/third sector. This would reduce the duplication of leaflets/information to carers, and improve the services offered to carers. Following good practice guidelines, and developing clear information and process pathways which are clearly communicated in initial and update training for staff, could help to limit information burden on carers whilst clarifying the latest information and legislative and practice requirements for service providers.

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Appendices

Appendix 1: Survey used in Phase 1

(formatting adjusted for purpose of the report)

Carer's Questionnaire.

Aberystwyth University is working in partnership with Ceredigion Social Services to investigate the take up of Carers Needs Assessments. If you are a carer, and are willing to participate in this study, I would be grateful if you would complete the brief questionnaire below and return it to me in the enclosed SAE.

Thank you for taking the time to consider completing this questionnaire.

Definition of a 'carer': "A carer is someone who looks after and supports a friend, relative or neighbour who could not manage without their help. This could be due to age, physical or mental illness or disability.

It does not mean a professional care-worker or personal assistant who gets paid for their work." (Directgov, 2011)

Please take your time to answer the following questions, Thank You.

SECTION A

Q1. Would you describe yourself as a carer?

Yes ☐
No ☐

Q2. If you answered yes to Q.1 are you on the Carers Register? i.e. you directly receive the carers newsletter Jigsaw.

Yes ☐
No ☐

Q3. Who do you look after/care for?

Tick all that apply

Parent ☐
Child ☐
Spouse ☐
Partner ☐
Other ☐

If Other please give details? _____

Q4. What is the main illness/disability of the person you care for/look after.

Q5. Do you care for more than one person?

Yes ☐
No ☐

Q6. Have you heard of a “Carers Needs Assessment”?

Yes ☐
No ☐

Q7. Have you ever been offered a “Carers Needs Assessment”?

Yes and I accepted ☐ go to section B
Yes and I declined ☐ go to section C
No I have not ☐ go to section D

SECTION B

If you answered, yes and I accepted, to Q.7

Q8.

a) How was the assessment delivered?

With the help of my social worker

With the help of another professional

Completed by myself

☐
☐
☐

b) How did you find the process?

Very easy

Easy

Neither easy nor difficult

Difficult

Very difficult

☐
☐
☐
☐
☐

c) How useful did you find the process?

Very useful

Useful

No useful

Not at all useful

☐
☐
☐
☐

d) How long did the process take?

30+ minutes

1+ hours

2+ hours

☐
☐
☐

e) Was this time

Too long?

Appropriate?

Too short?

☐
☐
☐

Is there anything else you would like to add?

Now go to Section E

SECTION C

If you answered yes and I declined, Q.7,

Q9. Can you tell us why you declined? (Tick all that apply)

Not appropriate for me

Too time consuming

I did not understand the process

I was put off by the opinions of other carers

I was put off by the opinions of social workers/ other professionals

Is there anything else you would like to add?

☐
☐
☐
☐

NOW GO TO SECTION E

SECTION D

If you answered, no I have not, to Q7

Q 10. Are you aware that you can request a “Carers Needs Assessment” ?

Yes ☐

No ☐

Is there anything else you would like to add?

SECTION E

Gender

Male

Transgender

☐
☐

Female

Prefer not to say

☐
☐

Age

18 – 25 ☐

26 – 40 ☐

41 – 50 ☐

51 – 60 ☐

60+ ☐

How would you best describe your occupation?

Tick all that apply

- | | |
|--------------------------|--------------------------|
| Full time carer | <input type="checkbox"/> |
| Employed, full time | <input type="checkbox"/> |
| Employed, part time | <input type="checkbox"/> |
| Self employed, full time | <input type="checkbox"/> |
| Self employed, part time | <input type="checkbox"/> |
| Retired | <input type="checkbox"/> |
| Unemployed | <input type="checkbox"/> |
| Student | <input type="checkbox"/> |
| Other | <input type="checkbox"/> |
-

Many thanks for taking the time to complete this questionnaire. All the information we collect is anonymised and is stored safely. We will not be able to identify you from the answers you give.

Completing the questionnaire will not affect any help you currently receive.

Appendix 2: Interview Schedule

Thinking about the carers needs assessment in full, both the process of filling it in and the outcomes from the assessment. Can you tell me your views on the value of this process and it's outcomes?

Now can you tell me your views on how this process is carried out?

In terms of the CNA, how do you feel about it in terms of the opinions of others? How do you feel the opinions of others have influenced your decision to fill in/ not fill in an assessment?

Can you tell me if there are any practical barriers /reasons/issues as to why you have chosen to not complete/ why you have chosen to complete?

Finally, it is important we get all the information we can as the purpose of this research is to highlight why carers do or do not complete the CNA

Is there anything else you would like to add, for example if you could inform policy writers what would be the most important issue you would like to address?

Appendix 3: Focus group Schedule

Tell us who you are, where you work and how you come into contact with carers?
(what you like to do in your spare time?)

In what capacity do you come into contact with the carer's needs assessment?

In your experience how do people go about conducting/ go through the process of completing the carers needs assessment?

- i) Over a period of time, days or weeks?
- ii) In one session?
- iii) A general chat with practitioner who then fills it in?
- iv) Carers complete unaided?

What are your feelings about the carers needs assessment?

So thinking about the CNA from your own perspective:

what are your views on the value of the CNA?

What is your perception of the process of conducting an assessment?

What are the perceptions of your colleagues towards this?

In your opinion what are the practical barriers to the process or on the flip side, why do you think people do go through with an assessment?

And now thinking about this from a carers perspective:

What do you think/believe is their perceived value of the CNA and the process of it?

Do you feel the perceptions of other carers influence them?

What do you think/believe that carers feel are the practical barriers/ reasons to complete?

So to bring this session to a close I'd just like get a few last points,

Of all the issues we have discussed which do you feel is the most important?

If you could give advice to policy and legislation writers of the CNA what would it be?

The main aim of this focus group was to help us evaluate the issues surrounding the CNA and how uptake could be improved. Is there anything we have missed or is there something else you would like to add?